



Cures in Our Lifetime

Since 2015, Future Forum Members have gone across the country engaging with and listening to thousands of millennials. We go where they gather, from small towns to large cities, on college campuses and at vocation schools, at startups and at big companies, and even in brew pubs and coffee houses. We have heard the challenges and aspirations of America's best educated, most diverse, and largest generation. A health care system that fails to work for American patients in the 21st century is an issue that continually arises. We hear about treatments that help symptoms but do not address underlying diseases, a system that does not connect or utilize modern technology, and a lack of diversity and opportunity within the medical community. These problems affect Americans faced with rare diseases, unsteady jobs, and bills that continue to pile up. Millennials believe access to a modern health care system is a public good, and not limited to being a private opportunity in America. We have listened and learned a lot about these issues. This generation wants to do big things and solve hard problems. Yet, they see a government that is incremental and providing no certainty for direction or funding. We must change that and unleash the unlimited potential of these collaborative minds. Now, we must act in Congress.

Future of Medicine: *Knows you, for you*

- **Genomics & Genetics:** The discovery of genomics and genetics has dramatically changed the medical community's approach to research and cures for cancer, multiple sclerosis, and other rare or complex diseases. Genomic and genetic testing can help medical professionals figure out the next steps for a patient – whether one type of treatment may be beneficial or harmful, or even help find the right drug dosage. There are potentially life changing benefits when patients are tested at birth rather than later in life. Minimizing a patient's diagnostic odyssey may lead to better health outcomes, reduced health care spending, and more time for families to spend together at home instead of a hospital. Genomic and genetic testing also may lead to a personalized medicine approach, instead of a one-size-fits-all treatment. Funding for medical research must support continued research and innovation in genomics and genetics research. We also must work with insurance companies to make sure the cures or treatments that result from this research are affordable to the patients that need them most. Finally, it is important to consider the ethics behind who has access to such data and how it can be used, shared, and protected.



- **Research Funding:** We can only cure what we can afford. After years of stagnant funding, Congress passed the bipartisan *21st Century Cures Act*, which boosted overall funding for the National Institutes of Health (NIH) and allocated \$4.8 billion over 10 years for a NIH Innovation Fund. The NIH Innovation Fund includes four initiatives: the Cancer Moonshot Initiative, the Precision Medicine Initiative, the Brain Research through Advancing Innovative Neurotechnologies Initiative, and the Regenerative Medicine Innovation Initiative. Discoveries and developments take longer than a fiscal year, so we recognize the importance of continuing to provide strong funding for the NIH and these initiatives. The United States used to inspire the brightest minds from not only our communities but around the world to teach and work in our research institutions. If we are to remain a leader in research, scientists need to trust that Congress will provide them with reliable, long term funding.
- **Regulations:** The Food and Drug Administration (FDA) must be as agile as the industries it regulates. To do so, it needs the proper resources and staff. Congress must continue to provide robust funding so that the FDA can respond appropriately and allow patients timely access to safe and innovative devices and drugs. We are proud of the work FDA does to establish standards and test wireless medical devices. We also recognize that small start-up medical companies may have difficulty navigating FDA regulations and would benefit from outreach by local FDA offices. We encourage FDA to use current staff or retain experts in their field offices who could work locally and in-person with start-up sectors or “innovation hubs” on demystifying regulatory pathways.

Technology: *Learn more, share more*

- **Apps:** Applications or “apps” help patients make appointments online, maintain prescriptions, and even chat with a medical professional instead of visiting the doctor’s office. Access to apps and other tools may encourage more communication between the patient and his/her doctor, which is a critical step forward to improving health over all. These apps can also help patients and providers keep track of the patient’s medical records, but it is important that the data collected is secure. Medical providers may want to incorporate the latest telemedicine into their practice but may discover that they will not be adequately reimbursed for those services. We need to work with agencies on how to update current reimbursement and regulatory frameworks for this innovative technology, while continuing to ensure secure data transfers and easy access for all Americans.



- **Data Sharing:** The more we share, the more we know, and the more we can cure. With an increased use of apps, data sharing has expanded not just between patient and doctor, but also between researchers. Successful trials are touted and published throughout the medical world, but what we would also like to see is an increase in sharing of the data and findings of failed clinical trials. Often times, in science and everyday life, we learn more from our failures. This can help save time, resources, and may inadvertently add use to another ongoing trial. We believe in balancing data sharing with patient protections. All data must be shared in compliance with the Health Insurance Portability and Accountability Act (HIPPA) and utilized with patient consent.
- **Updated Research Labs:** Scientists working to advance medical research are the first step to achieving cures in our lifetime. The way to find these modern cures is with modern technology. Scientists can greatly expand the utilization of these labs and how hard they work for Americans with mobile technology which allows them to run data or perform tasks even when the scientist is not present in the lab. When they come up short on the ability to modernize required equipment, they cannot focus on the results that a 21st century America deserves. It is critical that laboratories have the funding they need for upgrades and new equipment. As we debate comprehensive infrastructure legislation to mend our nation's roads and bridges, we should keep other infrastructure in mind as well, such as our laboratories, hospitals, and schools.

Diversity: A workforce as diverse as the generation they are helping

- **Medical Professionals & Researchers:** Young investigators, the next generation of scientists, should be able to trust that Congress believes in them and is committed to investing in their future and their impact on the future of health care. As an increasing number of students study in the STEM fields, we want to ensure that when they graduate, there are jobs in their area of expertise waiting for them. We recognize that with a highly competitive pool of funding for research, they may pursue jobs elsewhere if they do not feel confident about obtaining a job and working in their chosen field of research. Our institutions benefit from a workforce that encourages greater gender, ethnic, socioeconomic, religious, and generational diversity, and we must ensure that research jobs go to the best across all of these sectors. Student loan debt often hinders a future researcher's or provider's ability to work in underserved communities and underrepresented fields. We support federal loan repayment programs to help students focus on the futures they want instead of the debt they have.



- **Clinical participants:** For far too long, clinical trial participants did not reflect the diversity of the United States. Testing treatments on one narrow demographic does not necessarily mean those treatments are safe and effective for everyone. Future Forum believes we must continue to remove barriers and rebuild trust with historically underrepresented groups in clinical trials. We appreciate updated FDA guidance that clarifies financial assistance with travel and lodging costs for clinical trial participants does not present an undue influence and recognize that this helps to expand diversity in trials without limitations based on financial status. We support further discussions aimed at reducing disparities and increasing access to clinical trials, especially for those with rare diseases.